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**Ethical duties of nephrologists: when patients are
nonadherent to treatment**

Jordan A. Parsons, Dominic M. Taylor, Fergus J. Caskey & Jonathan Ives

Abstract

When providing care, nephrologists are subject to various ethical duties. Beyond the Hippocratic notion of doing no harm to their patients, nephrologists also have duties to respect their patients' autonomy and dignity, to meet their patients' care goals in the least invasive way, to act impartially, and, ultimately, to do what is (clinically) beneficial for their patients. Juggling these often-conflicting duties can be challenging at the best of times but can prove especially difficult when patients are not fully adherent to treatment. When a patient's nonadherence begins to cause harm to themselves and/or others, it may be questioned whether discontinuation of care is appropriate. We discuss how nephrologists can meet their ethical duties when faced with nonadherence in patients undergoing haemodialysis, including: episodic extreme agitation, poor renal diet, missed haemodialysis sessions, and emergency presentations brought on by nonadherence. Further, we consider the impact of cognitive impairment and provider-family conflict when making care decisions in a nonadherence context, as well as how the COVID-19 pandemic might affect responses to

nonadherence. Suggestions are provided for ethically informed responses, prioritising a patient narrative approach that is attentive to patients' values and preferences, multi-disciplinarity, and the use of behavioural contracts and/or technology where appropriate.

Key words

Autonomy; Dialysis; Ethics; Kidney failure; Nonadherence; Patient-centred care

Introduction

A nephrologist's duty of care to patients is rooted in the Hippocratic tradition, requiring them to have their patient's interests at heart and not to harm them. However, it is not always clear how to satisfy this duty in circumstances such as, for example, when a patient must choose between two treatments with limited evidence of comparative effectiveness, when a patient is nonadherent to their current treatment, or when a patient is cognitively impaired. In approaching such situations, it is important to recognise that the duty of care encompasses several distinct duties, which must be navigated and weighed when making complex care decisions. These include the widely familiar duty of nonmaleficence, but also duties such as respecting patient dignity and autonomy, and meeting care goals in the least restrictive way possible (see **Table 1**). These duties will inevitably conflict at times, but that does not undermine their value; complex situations call for complex solutions, and trade-

offs may prove necessary. In this paper, we will consider these duties in relation to patients receiving dialysis who have persistent issues with adherence.

Patients with kidney failure who begin dialysis therapy generally do so in their best interests. Whether by the informed consent of the patient or, in the case of those without decision-making capacity, a decision taken on their behalf, it is started because it is deemed appropriate and clinically beneficial for the patient. However, whilst many undergo regular therapy without issue, some opt not to fully engage with agreed treatment [1,2], which raises a series of ethical concerns [3]. This is in part because dialysis, perhaps more than many treatments for other chronic conditions, is intrusive and can prove hugely disruptive to a patient's life, resulting in what Curtin and colleagues have described as the 'compliance-independence tight rope' (p. 53) [4]. That being said, reported levels of dialysis nonadherence will be affected by the fact that it is more visible than, for example, drug nonadherence.

Causes of dialysis nonadherence are multifactorial [5], and it may manifest in various forms [6]. Some are harmful only to the patient in question, such as missed sessions/early departure, poor care of dialysis access, and nonadherence to an appropriate diet and/or medication. Others, however, affect clinical staff, other patients, and those accompanying patients to dialysis clinics. For example, late arrival, emergency treatment (made necessary because of prior nonadherence), and disruptive/abusive behaviour during sessions (such behaviour may not always be characterised as nonadherence, but we include it

as a milder form). Johnson and colleagues discuss acts of nonadherence as a four-point continuum: (1) the patient is only harming themselves, (2) the patient is harming themselves and inconveniencing others, (3) the patient is verbally abusing others, and (4) the patient is physically abusing others (p. 78) [7]. Whilst this continuum may be taken as representing escalating seriousness, it is better understood as describing forms of nonadherence as each could be more or less serious depending on precise circumstances. When making decisions in light of nonadherence, then, there are considerations beyond the impact on the patient in question, and the appropriate response will vary depending on both where along the continuum the patient's nonadherence falls and its seriousness.

When faced with a patient with adherence issues, it is understandable that the nephrologist will feel frustration. From their perspective, they are trying to help the patient and may struggle to comprehend why the patient is not being receptive. However, this frustration causes its own problems. As noted by Balint, nonadherent patients are 'often labelled as hateful, difficult, or uncooperative and then treated accordingly' (p. 28) [8]. It is the nature of that "accordingly" that we will explore in this paper, considering the appropriate response when a patient is nonadherent with dialysis. Of note, our focus is on patients receiving in-centre haemodialysis (HD). Whilst patients on peritoneal dialysis may also be nonadherent by, for example, missing exchanges [9], different ethical issues arise because such patients undergo treatment at home.ⁱ

ⁱ This applies also to patients undergoing at-home HD.

Further, we acknowledge that we are approaching this from the perspective of a Western, high-income country with a publicly funded dialysis service. Some of our discussion will have universal significance, but we note that there will be further complications when patients are nonadherent in low- and middle-income countries [10], and in non-Western cultures many of the autonomy-focused approaches we discuss could be less relevant [11,12].

In this paper we will discuss the cases of two fictional patients: Ms A and Mr B. Ethically defensible responses to HD nonadherence will be discussed throughout, then revisited as we conclude with recommendations.

Table 1. Key ethical duties of nephrologists

Ethical duty	Nonadherence considerations
Respect for autonomy: To respect the right of a competent patient to make informed, voluntary decisions about their own care in accordance with their values and preferences.	<ul style="list-style-type: none"> ▸ Has the patient expressed a desire for dialysis? ▸ Has the patient provided reasons for their nonadherence? ▸ Does the patient have the capacity to make decisions about their care?
Nonmaleficence: To do no harm to a patient. This includes not providing care that the nephrologist does not consider appropriate.	<ul style="list-style-type: none"> ▸ Is the nature of the patient's nonadherence harmful to them? ▸ Are other patients potentially harmed by the patient's nonadherence?
Beneficence: To do what is beneficial for the patient, with a focus on maximising benefits whilst minimising harms.	<ul style="list-style-type: none"> ▸ Are there actions that can be taken to address the patient's nonadherence that would be in the patient's interests?

Respect for dignity:

To recognise when the provision of certain care (particularly when not delivered in private) might be undignified for the patient, and to avoid this where reasonably possible.

- Do the measures taken to allow dialysis delivery (i.e. restraint) undermine the patient's dignity?
- Do other patients witness these measures?

Proportionality:

To provide the care that achieves care goals with the least infringement/in the least restrictive way.

- Are there alternative methods of delivering dialysis that are less invasive?
- Might the patient's care goals be met by non-dialytic care?

(Distributive) justice:

To act impartially and avoid inequalities where possible, ensuring that resources are allocated justifiably.

- Are significant resources needed to overcome the patient's nonadherence?
- Will other patients have to forego care if means of overcoming the patient's nonadherence are pursued?

Ms A (1): Fluctuating decision-making capacity, extreme agitation, and poor diet

Box 1. Ms A

Ms A, a 65-year-old woman with a history of craniopharyngoma resected in childhood develops progressive chronic kidney disease of uncertain cause and is found to have atrophic kidneys on imaging. She starts renal replacement therapy in the form of in-centre haemodialysis.

Her previous brain surgery has led to other psychiatric problems including problems with impulse control and compulsive eating. The majority of the time she demonstrates capacity to make decisions about her treatment and is very clear she wishes to continue haemodialysis. However, her mental state deteriorates intermittently, and this leads to episodic extreme agitation on dialysis where she represents a risk to herself and others. During a typical episode she may remove dialysis needles without warning, demand specific foods and drinks, or throw food and hot drinks at staff members. In this situation, emergency help is given including

stopping the dialysis session to reduce the risk of harm. For some periods, she has been denied hot drinks in order to maintain staff safety, but this has led to increased agitation and likelihood of her pulling out dialysis needles.

These behavioural problems lead to poor control of dietary factors on dialysis (high potassium intake, high phosphate intake) and suboptimal dialysis dosing (from reduced time on the machine). There is also difficulty maintaining permanent dialysis access – her upper limb AV fistula is damaged irremediably when a needle is removed during an episode of agitation, and a repeat episode is felt to be very likely. Ms A also prefers being attached to the dialysis machine via a line because it means she can use both of her hands while on the machine. As such, no further fistula formation is planned, leaving her receiving dialysis via a central venous catheter, further reducing dialysis adequacy and increasing Ms A's risk of infection.

First, Ms A's fluctuating decision-making capacity. Essentially, she is expressing two conflicting choices regarding her HD depending on her mental state at the time. When she is (cognitively) well, she is clear that she wants to continue HD, but can quickly become resistant during sessions. This raises the question of whether the capacious choice of Ms A to receive HD is reason enough to disregard her clear objections during sessions. In seeking to respect Ms A's autonomy, it may not be clear which of her expressed desires (be they verbally or physically manifested) is "most autonomous".

To determine the "most autonomous" preferences in such a situation, one can consider the idea of first- and second-order preferences presented by Dworkin [13]. Simply put, first-order preferences are unreflective, and second-order preferences are reasoned. Applied to Ms A, her resistance to HD can reasonably be considered her first-order preference, whilst her usually expressed desire to continue her treatment is her second-order preference. Given that reason is widely considered a necessary element of autonomous action, we

can conclude that Ms A's desire *for* dialysis is more autonomous than her occasional – apparently impulse driven - resistance.ⁱⁱ However, the question remains of how to respond, because restraint – which is perhaps the most obvious and *prima facie* simplest way to respect Ms A's second-order preference for HD – may not be considered proportional.

Whereas all reasonable efforts should be made before considering restraint – including the use of a sitter during her HD sessions – with Ms A it might be felt that there are four options:ⁱⁱⁱ

- (1) Her autonomous choice to undergo HD is respected, meaning her objections to care during sessions are ignored. Physical and/or chemical restraint will be used to provide care if necessary.
- (2) Her autonomous choice to undergo HD is respected, meaning her objections to care during sessions are ignored. At the same time, her capacious request to undertake physical and/or chemical restraint to provide care if necessary is respected.
- (3) Her autonomous choice to undergo HD is respected, meaning her objections to care during sessions are ignored. However, it is agreed that

ⁱⁱ One might present this as dichotomous, with a desire either being autonomous or not. However, we treat Ms A's autonomy as a spectrum to not disregard the importance of her occasional resistance to treatment.

ⁱⁱⁱ An earlier iteration of these options is contained in a blog post by one of the authors. See Parsons JA. Ethical issues in restraining patients for dialysis. Available: <https://openjusticecourtofprotection.org/2020/10/21/ethical-issues-in-restraining-patients-for-dialysis/> [accessed 8 Dec 2020].

the decision will be revisited if physical and/or chemical restraint becomes necessary to provide care.

- (4) Her autonomous choice to undergo HD is respected only when it is expressed, meaning that when she resists HD it will not be provided.

In respecting Ms A's autonomy, option (4) appears inappropriate as it fails to fully respect her "most autonomous" preference. In choosing between the remaining options, a narrative ethics approach is useful, seeking to understand Ms A's values and preferences as they relate to her treatment. The nephrologist should, through discussion, seek to establish the reasons for her nonadherence and her care goals, and her feelings about restraint. Even though her agitation is linked to her psychiatric problems, it may be that small (or significant) adjustments to her environment will reduce the frequency or severity of these episodes. For example, it may be feasible for her to be dialyzed alone in a side room or have her dialysis rescheduled for a quieter shift/unit. Further, for effective shared decision making it is important that all options – including discontinuing HD and being managed palliatively – are properly discussed with Ms A to ensure respect for her autonomy [14]. The challenge of restraint for treatment (and, indeed, other elements of her nonadherence) would be avoided if, through effective dialogue, Ms A decides that discontinuing HD and being managed palliatively better meets her care goals – but she must in no way be pressured into making this choice just because the clinical team are reluctant to

use restraint.

Should such changes not prevent Ms A's agitation, but it is established (which seems likely) that her care goals clearly indicate continued outpatient HD, it may be feasible to establish a Ulysses pact with her. A Ulysses pact (also referred to in this context as an advance directive) entails an individual freely making a decision to later be bound by that decision, in anticipation of being unable to make autonomous choices; it can cover things a patient *does* want as well as things a patient *does not* want. This would enable the autonomy of Ms A to be respected by her agreeing to measures that enable her care goals to be met in line with her values and preferences – assuming, that is, that she consents to restraint when she has decision-making capacity and fully understands the impact of such restraint. In such a scenario, the duty of proportionality can be considered met. It would be important for an advance directive like this to describe the specific circumstances in which Ms A would want dialysis to cease if she loses capacity. One of the challenges of these kinds of advanced directives is ensuring that they cover the full range of possible eventualities, as they will tend to lose force outside of the specific circumstances described. It would also be important to revisit any Ulysses pact after each episode of restraint to confirm that it still aligns with Ms A's values and preferences.

This approach would be in keeping with patient-centred care and has been tacitly endorsed in a recent case in the England and Wales Court of Protection involving a similar situation regarding conflicting choices. In *Re*

AHK, a patient with a severe personality disorder similarly expressed a clear desire for HD when well, but frequently refused care at the time of delivery [15]. The Court refused the hospital's application to provide HD only when the patient was adherent (option (4) above) and authorised both physical and chemical restraint to provide dialysis (option (1) or (2) above). Option (2) – whereby a Ulysses pact is established – is preferable to (1), because it better respects the patient's autonomy.

The conflicting preferences of Ms A are not the only concern. In deciding between these options, it is necessary to account for the nature of her occasional extreme agitation during HD sessions and the associated risks. This agitation is linked to her fluctuating decision-making capacity in that it arises only when her mental state intermittently deteriorates. Such actions present a risk of harm not only to Ms A, but to all those present, including staff, other patients, and any family and friends who may have accompanied patients. In addition to the potential physical harm from Ms A's behaviour, other patients may find it highly distressing if they witness her being restrained to receive dialysis – particularly if it appears to them that such treatment is against Ms A's will.

Ms A's nephrologist has a duty to her during these episodes, requiring that they act in her best interests. Assuming, for now, that her decision to continue with HD is taken as truly reflective of her values and preferences and her nephrologist is thus bound by it, it is clear that the continuation of HD even

in the face of her agitation is in both her medical and wider best interests. However, the risks to others must be considered; whilst not continuing to provide Ms A with care puts her life at risk, her nephrologist has the same duties of beneficence and nonmaleficence to all patients [8].

In situations when a patient's nonadherence is potentially harmful to others, the ideal solution is to establish an effective behavioural contract. However, this does not seem appropriate to Ms A's case as her extreme agitation is a result of her temporarily deteriorated mental state.^{iv} Instead, Ms A's dialysis schedule could be tailored to reduce agitation. For example, if she becomes most agitated in the final hour of her sessions then they could be shortened. If this is done, an additional weekly session could be scheduled to maintain her dose; this may be too burdensome for Ms A so may not be in her best interests, and a reduced dose for this reason is ethically defensible if appropriately balanced against the risks, such as higher mortality [16]. Tailoring Ms A's HD schedule may also give her a sense of control over her treatment that results in greater adherence with other aspects of her care [17], meaning the apparently counterintuitive approach of reduced HD could result in better care overall. Indeed, and as O'Hare notes, ultimately, '[t]he person comes first' (p. 486) and patients may consider things such as ability to travel more valuable; it is about how "adequacy" is understood [18].

A third consideration is Ms A's poor diet. Notably, she has a diet that is

^{iv} We will revisit the role of behavioural contracts shortly.

not likely to result in her meeting target phosphate or potassium levels [19]. Her demands for particular foods during her HD sessions might be simply dealt with by refusing the requests. This can be justified not only on the basis of nonmaleficence because the foods requested might adversely affect Ms A's condition, but also the fact that there is no wider duty on nephrologists to meet specific requests for food (even if requests were for a food that has no notable impact on patients receiving HD, nephrologists can justifiably refuse them). However, such an aggressive approach should be avoided as it damages the patient-provider relationship (which is especially important in chronic care). Further, it only affects Ms A's diet during sessions; her diet at home may be high in potassium, so enabling (but not forcing) her to address the cause is important.

Whilst she will have had conversations with her care team about it, Ms A may not fully understand the risks associated with a high-potassium diet for patients with kidney failure. It is ultimately her decision whether to maintain a problematic diet, but to satisfy the duty of beneficence her nephrologist should be confident that it is an informed decision. Further education or the involvement of a dietician may be appropriate. It is also important to consider external constraining factors, such as finances. It may be that Ms A cannot afford a renal diet [6], or it may be hard for her to access or prepare appropriate food – and she can perhaps be supported in this. If, after these efforts, Ms A continues her high-potassium diet, her nephrologist must respect her

autonomous choice to do so. Of course, if her diet was such that potassium levels were maintained at life-threatening levels even whilst receiving a significant dose of dialysis, this might result in a situation where continuing HD is essentially futile – but this is not the case. Her current situation may still result in occasional episodes of life-threateningly high potassium levels, but she could nonetheless live for many years with these high levels of potassium, albeit at increased risk.

Ms A (2): Deteriorating condition and provider-family conflict

Box 2. Ms A continued

Dialysis continues for many years. After some discussion she agrees to have an arteriovenous graft formed in her thigh which is used successfully for dialysis. Unfortunately, when aged 70, she suffers a large stroke, causing significant physical disability as well as increasing episodes of distress. She is now regularly transferred to dialysis sessions on a stretcher, in an ambulance. She no longer demonstrates capacity to make decisions about ongoing dialysis treatment. Episodes of severe agitation during dialysis are now more common and increasing in frequency. Members of the dialysis nursing team report feeling uncomfortable providing dialysis for Ms A because of her apparent distress and risk of harm to herself and others. Most dialysis sessions are curtailed because of a risk of her removing needles, and the dialysis team are concerned that restraint may become necessary to allow safe dialysis to proceed. Her supervising nephrologist holds a family meeting to discuss the situation with Ms A's family. The opinion of the clinical team is that dialysis is objectively causing distress and that this should be discontinued. Ms A's family hold the view that her previously expressed opinion to continue dialysis remains relevant and wish for dialysis to continue even if restraint is required.

Given the deterioration of Ms A's condition, it is very possible that dialysis is

no longer in her best interests. It is important, however, that this is not assumed without due consideration, else there is potential for discrimination.

From a distributive justice perspective, the provision of futile interventions entails costs which will affect the availability of care for other patients, so it is important that dialysis be provided only when clinically appropriate [20]. Furthermore, from a patient perspective, providing futile treatment that is invasive and distressing is unlikely to be beneficial. However, Ms A's HD continues to serve its clinical purpose even if it does cause distress, so it cannot be considered futile.

Given that continued HD cannot be considered futile, a patient in Ms A's situation should be permitted to continue HD if, accounting for her own care goals, she feels the benefits outweigh the harms. However, now that Ms A has lost the capacity to make decisions about the continuation of her treatment, respecting her autonomy becomes more challenging as she, in effect, no longer has autonomy to respect. Such a change in her condition means that her previously expressed values and preferences may no longer be accurate and, whilst she may still be able to communicate care preferences, her lack of decision-making capacity means that these should not be unquestioningly followed. Here, the principles of beneficence and respect for dignity may come to the fore. Her having agreed to an arteriovenous graft being formed in her thigh further supports the case for her autonomous preference being *for* HD, but her deterioration may have caused a capacitous Ms A to choose to discontinue

HD.

Different jurisdictions will require different responses when a patient lacks decision-making capacity. Whereas the decision would fall to the family in many countries, in others – such as England and Wales and Singapore – it would fall to the patient’s nephrologist in the absence of a formally appointed decision maker. Nonetheless, even if the decision does fall to the family, the patient’s nephrologist should advise the family on what they consider appropriate. Further, the decision maker should adopt a holistic view of what is in the patient’s best interests that accounts for their values and preferences rather than exclusively considering the patient’s *medical* best interests.

Nephrologists may be hesitant to discontinue HD even if the patient’s behaviour is dangerous as such care may be viewed as a non-contingent entitlement [7]. As a life-sustaining therapy for those with a chronic condition, HD is viewed as a *necessity* in many countries. Nonetheless, HD is not always in the best interests of a patient [21]. There are many factors in Ms A’s case that may suggest HD discontinuation and palliative care to be more appropriate. In considering this, the nephrologist might look to the equivalence thesis.

The equivalence thesis posits that, all things equal, there is no morally relevant distinction between withholding and withdrawing care [22]. Consider, then, a patient (Ms X) in a similar clinical and lifestyle condition to Ms A (having had a disabling stroke), but for whom HD has not yet started. Ms X has demonstrated similarly high levels of distress in other aspects of her care, such

as when having a phlebotomy. If it would not be considered clinically appropriate for Ms X to *begin* HD, the equivalence thesis would conclude that the *continuation* of Ms A's HD is not clinically appropriate. Similarly, assuming that Ms A and Ms X are sufficiently similar in relevant ways, if it would not be considered in Ms X's best interests to *begin* HD, then the equivalence thesis would hold it cannot be in Ms A's best interests to *continue* with HD. Ms A's clinical team believe that the level of distress HD is causing her is now such that discontinuation is appropriate, as her HD is doing more harm than good. Assuming the clinical team would oppose the provision of HD to the relevantly similar Ms X, this is justifiable. However, it is important that Ms A's clinical team are not motivated by a desire to discontinue her care because of her disruptive behaviour; it must be a decision made in *Ms A's* best interests.

Accounting for the possible harms of restraint in determining what is in Ms A's best interests is required. It has the potential to hugely affect her psychologically; post-traumatic stress disorder is ordinarily a concern in HD patients [23] and may feasibly be exacerbated by physical restraint. This is especially important to consider when the patient is not able to consent to restraint themselves [24]. That is not to say that restraint cannot be justified, but it can only be justified in terms of the benefit to the patient; a patient's best interests cannot be determined with reference to harm to others. As such, further attempts to reduce Ms A's nonadherence with psychosocial approaches are appropriate at first, as well as again reconsidering the length and frequency of

her dialysis sessions. Restraint should always be reserved as a last resort, but this is especially important when a patient lacks decision-making capacity as it is to a greater degree inflicted on the patient rather than agreed upon.

All these factors should be discussed with Ms A's family regardless of the jurisdiction. No matter who ultimately holds decision-making authority, consensus is preferable because this is better for all involved. The family will generally provide an understanding of the patient's values and preferences that the clinical team lacks, and even within the clinical team a range of perspectives is important as, for example, the way nephrologists and nurses interact with patients differs.

Finally, there is the question of potential moral distress to members of the clinical team because of conflict between them and Ms A's family. Moral distress is the experience of psychological distress caused by a moral event [25]. In Ms A's case, that might result from a dialysis nurse having to continue to provide HD that they do not consider ethically appropriate because of external constraints (made worse by the experience of Ms A's suffering and nonadherence). This is especially a concern in jurisdictions where the family are acting as decision maker, because of the lack of input the nurse may have in that decision. Whilst the potential for moral distress to clinical staff is not an ethically justified factor in a decision about patient care, it is important for the clinical team to understand and respond to it [26].

Mr B (1): Missed sessions and emergency presentation

Box 3. Mr B

Mr B, a 35-year-old man with a history of established kidney failure from childhood nephrotic syndrome related to focal segmental glomerulosclerosis (FSGS) receives in-centre haemodialysis. He had a kidney transplant in childhood with an episode of acute cellular rejection causing graft failure several weeks after the transplant surgery. Further transplantation has been precluded by poor adherence with treatment. He regularly uses illicit drugs, has a chaotic lifestyle, and is well known to the hospital security staff and police for relatively minor crimes committed on and off the hospital site. He expresses clearly and with capacity a decision to continue life-sustaining dialysis treatment but, at least weekly, is absent from scheduled dialysis sessions (prescribed thrice-weekly). Typically, in the 48 hours after missing a dialysis session, he will present to the emergency department with severe, life-threatening hyperkalaemia, or pulmonary oedema and need emergency dialysis. On occasion, because of haemodynamic instability or requirements for ventilator support, this care is delivered on the intensive care unit. This pattern develops into a routine such that it is normal (over months and years) for him to miss at least one weekly dialysis session and attend instead as an emergency. This pattern of care use leads to regular loss of a routine dialysis slot, as well as regular use of an emergency dialysis slot, at the expense of other urgent inpatients requiring dialysis. The team make efforts to prevent this ongoing pattern through discussion with the patient (who maintains a wish to continue regular treatment but continues with the same pattern of behaviour) and through provision of an additional weekly dialysis slot to give more flexibility (leading to him missing two dialysis slots rather than one).

A patient narrative approach is fitting in this scenario, with a focus on being non-judgemental and not blaming Mr B for his situation. Fiester writes that '[h]ostility, anger, depression, anxiety, and even noncompliance are common reactions to difficult circumstances, even among the psychologically healthy and typically well-adjusted' (p. 2) [27]. Whilst there is usually an element of choice to HD nonadherence, it is important to recognise the impact such

demanding care can have on a patient and how it can fracture the provider-patient relationship. Patients who do not engage in care the way their nephrologists expect are often viewed in a condescending way [28], which can lead to patient anger [29]. The inherent vulnerability of patients does not necessarily absolve them from wrongdoing [30] but must be appreciated as potentially contributing to adherence issues. Recognising Mr B's situation as requiring a shared decision rather than an intervention is not only more likely to yield lasting results but is more respectful of his autonomy [31], particularly given his apparently autonomous desire to continue HD.

Understanding the reasons for Mr B's behaviour will likely prove productive in helping to ascertain an appropriate way forward. Kahn notes that informally interviewing a patient can prove cathartic for the patient [32]. Similarly, affording Mr B an opportunity to share his story with the clinical team in a non-judgemental environment may improve the provider-patient relationship and instil trust. Ideally, this would include other teams involved in Mr B's care – such as the intensive care team that occasionally provides ventilatory support – as it is also important that they understand his values, preferences, and care goals. Where appropriate, involving a psychologist may also be beneficial [33]. Suggestions that this approach will result in 'transformed conduct on the part of the patient' (p. 4) [27] seem exaggerated, but there is at least potential for some improvement. With conversation being minimally invasive (assuming any request by Mr B to end the conversation is

respected), this patient narrative approach as a first choice satisfies the duty of proportionality.

In addressing underlying causes, the renal team could also make reasonable efforts to help Mr B in controlling his drug use – such as a referral to drug services – which may help in gaining his trust and cooperation [8]. A multi-disciplinary approach enables a high level of support [34] and may prove more successful in the long term – particularly for patients with long-term patterns of nonadherence – than efforts by only the renal team. Given that Mr B's drug use may be affecting his ability to agree to and adhere to a revised care plan, addressing it may enhance his autonomy by improving his ability to make a reasoned and informed decision about his behaviour based on his values and preferences. Efforts to do so must, however, be conscious of Mr B's vulnerability in the situation; he may feel judged for his drug use so the issue must be approached sensitively to respect his dignity.

Another approach that may be suitable for Mr B is the use of mobile technologies to improve education and, in turn, adherence. A 2015 study found that a system of automated SMS texts and voice messages was effective in reducing the number of missed HD sessions [35]. Whilst this study included only a small number of patients, it at least demonstrates the potential of such methods. A recent review of patient-facing smartphone apps for chronic kidney disease also highlighted several with a focus on patient education [36], which itself may improve adherence. Using technology in this way may not only be

ethically *defensible*, but ethically *required*. The telemedical imperative holds that given the benefits of such technologies, healthcare systems have a duty to seriously consider their implementation provided they are safe, effective, acceptable to patients, and raise no other service-specific concerns [37]. Similarly, assuming Mr B consents to the use of such an approach, the negligible burden would also satisfy the duty of least infringement (proportionality). Patients such as Mr B may be considered *too* nonadherent to benefit, but if such simple interventions can be included as part of a behavioural contract then the possibility of them contributing to a reduction in nonadherence is justification enough for their use.

Following these interventions, establishing a behavioural contract with Mr B should become more feasible. Not only does an effective behavioural contract prevent the need for potentially damaging conversations about either forced care or the discontinuation of care, but it maximises the patient's autonomy in the situation; the patient is agreeing to a way forward rather than being instructed. As such, it may empower the patient [34]. Psychosocial interventions like this have been suggested as suitable early interventions to avoid escalation when the patient's nonadherence is mild [7,38]. In establishing a behavioural contract, it should be noted that Mr B appears to have an expectation of treatment at his leisure, regardless of the impact on others. Whilst this could be viewed as an understandable expression of his anger [8], it is nonetheless ethically problematic. However, particularly in publicly funded

healthcare systems, patients themselves have a duty ‘not to use health services casually’ (p. 345) [30], the breaking of which becomes more problematic as the services in question get closer to acute medical services. It would be appropriate to remind Mr B of this duty as a reason why a behavioural contract is important.

Beyond the harm Mr B’s behaviour poses to himself, there are other pertinent considerations. The additional HD sessions allocated to Mr B entail further costs. His non-attendance and subsequent presentation as an emergency mean that Mr B’s care is using more resources – especially relative to other HD patients. This will inevitably result in resource compromises elsewhere, raising legitimate questions around distributive justice.

Various models exist for the allocation of scarce resources, including lotteries, prioritarianism, utilitarianism, and approaches based on reciprocity [39]. However, decisions based on distributive justice at the patient level are ethically problematic because they undermine both the integrity and trust central to the provider-patient relationship [40]. As such, these models are most appropriately applied at a broader (system or policy) level. This does not, however, preclude discussing with Mr B the impact of his behaviour on others, and reminding him that his actions waste precious resources. Intentionally and maliciously wasteful behaviour could legitimately be responded to with sanctions – such as refusing treatment. However, such sanctions should always be a last resort and given the vulnerable position of patients like Mr B would rarely be appropriate.

Mr B (2): Continued nonadherence amidst the additional pressures of the COVID-19 pandemic

Box 4. Mr B continued

The situation continues as before, with a routine of ongoing missed regular dialysis sessions followed by emergency presentation with life-threatening hyperkalaemia. The 2020 COVID-19 pandemic ensues. This situation raises two further issues:

- i) Acute dialysis services are under intense pressure to be able to continue to provide dialysis while maintaining time-consuming infection control procedures during the pandemic.
- ii) Intensive care services are under current and anticipated extreme pressure to provide care to a large number of patients infected with the virus. Previously agreed and individualised criteria around the suitability for intensive care admission are changing in light of the reduced resource available.

The COVID-19 pandemic has raised many ethical issues in the provision of kidney care [41,42], and might result in the balance of benefits and harms being shifted in the context of HD patients with adherence issues. Mr B's frequent, unscheduled arrivals at the hospital as an emergency now present the additional risk of COVID-19 infection and place avoidable pressure on services already close to breaking point. As such, Mr B's actions may now be considered to have moved beyond being disruptive to the point of being dangerous.

If the additional risks were only to Mr B, the fact that he has decision-making capacity and has expressed his preferences clearly would require his

autonomy to be respected. Further efforts to educate him as to the risks would be appropriate in assisting him to make a fully autonomous (informed) decision, but it would ultimately be a matter of Mr B taking responsibility for his own health. However, the undue risks to others introduced by his actions invoke other ethical duties that must be balanced.

Mill's harm principle stipulates that 'the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others' (p. 22) [43]. This principle centres on individual liberty, which can be taken as autonomy in the medical context. As such, it holds that a patient with no pertinent cognitive impairment is free to act in a way that is detrimental to their own health, but should their actions pose a risk to others it is justifiable to (proportionately) interfere with their ability to do so. In more familiar language, it becomes a question of autonomy (applied to Mr B) versus nonmaleficence (applied to the other people at the hospital). Understandably, Mill's harm principle has been tacitly invoked throughout the COVID-19 pandemic. For example, requiring patients to wear face coverings in hospitals is to exercise power over them to prevent harm to others. But how might it apply to Mr B's situation?

First, it can be dismissed as justifying the discontinuation of Mr B's HD (including the denial of emergency care). As noted above, the harm principle permits *proportionate* interference. Given that discontinuation of Mr B's care would ultimately result in his death, it cannot be considered a proportionate

response to the risks of harm his behaviour creates. The nephrologist is ultimately seeking to continue Mr B's care whilst preventing harm coming to others, and various measures might be tried to achieve both.

Even if alternatives are exhausted, the discontinuation of Mr B's HD is undermined unless the decision is also taken to refuse him emergency care when he needs it; if his HD were discontinued, his condition would inevitably deteriorate to the point that emergency care would be required to save his life. The refusal to provide emergency care would rarely be ethically justified because of the nephrologist's role of 'captive helper' (p. 350) [30]. This difficulty is demonstrated by the 1982 case of *Payton v Weaver* in the US, in which the judge ruled that the patient's failure to keep to an agreed package of care meant that the nephrologist no longer had a duty to provide chronic HD, but that emergency HD should still be provided if necessary [44]. This distinction is, in practice, irrelevant with care such as HD. Mr B's chronic HD and emergency HD must be treated as one if discontinuation is considered, and such discontinuation would seldom be justifiable.

Whilst harm to others does not justify the discontinuation of Mr B's care, the question of distributive justice remains because Mr B's emergency presentations require care that is in short supply. The same models outlined above may be considered, and they have been discussed as applicable to kidney care in the COVID-19 context elsewhere [41]. However, whilst the pressure on resources has increased, it remains that they should not be considered at the

patient level. They may introduce a risk of prejudice in the COVID-19 context as nephrologists may be increasingly frustrated with behaviour such as Mr B's and be less inclined to divert resources to patients who are having a negative impact on service provision "by choice". Instead, it makes sense to again consider the equivalence thesis in relation to Mr B's scheduled HD, accounting for any wider changes to allocation systems. The fact that his emergency presentations sometimes also require respiratory support means that wider COVID-19 resource allocation guidelines will likely apply, and Mr B would inevitably be affected by those – but on an equal footing with everyone else.

Finally, in continuing the patient-centred approach and seeking to enhance Mr B's autonomy, before any decisions are made about his care it is important that Mr B is made aware of the change of circumstances and what this means for his care if his nonadherence continues. It should be made clear to Mr B that, given additional resource pressures, it may not be possible to dialyze him immediately should he continue to present as an emergency. Attempts might also be made to revisit behavioural contracts in light of the significant change in circumstances.

Conclusion

It is important to remember amidst all the rhetoric of the duties of nephrologists that patients too have duties. As argued by Draper and Sorell, '[a]utonomy without responsibility is not autonomy' (p. 340) [30]. Patients need to recognise

that they are not free from obligations when they access care, and respecting those providing care, as well as other patients, is key among them. That being said, the duty of care owed by nephrologists generally wins out over patient accountability for wrongdoing in practice.

Whilst there is undoubtedly a point at which a nephrologist's duty to provide care for a particular patient is exhausted by that patient's nonadherence, reaching that point should be rare. Before discontinuing a patient's care, it is important to be absolutely sure that one has 'left no stone unturned' (p. 29) [8]. As such, when faced with any form of nonadherence the first response should be to attempt to ascertain the cause, address it, and prevent it escalating.

Ultimately, it is important that all dialysis providers have clear policies on managing nonadherence patients that all staff are trained on [6] and that patients are educated about. This avoids the need for complex situations – such as those of Ms A and Mr B – to be navigated solely by the clinical team at the time. However, a 2000 study in the US found that only 51% of participants (healthcare professionals involved in kidney care) felt that they had received adequate training to deal with these complex situations, and 40% reported that their HD unit lacked a written policy [45]. Some providers may still lack appropriate policies and training. Local guidance should be developed in line with relevant laws and reflection on key ethical considerations. It should exist independent of any wider guidance on challenging behaviour from patients so that issues specific to HD nonadherence are addressed.

There are many approaches to improving HD adherence, which will have varying success depending on the patient and the nature of their nonadherence. Several key approaches have been discussed in relation to the cases of Ms A and Mr B, but we have not provided an exhaustive list. Further psychosocial interventions have been outlined by Krespi, including cognitive behavioural therapy and mindfulness meditation [38]. We provide recommendations for ethically informed approaches in **Box 5**.

Some of the approaches to addressing nonadherence may result in a care plan that is, from a clinical perspective, less than ideal. However, the importance of patient-centred care must be recognised, and respecting patient values and preferences that reduce nonadherence may be overall preferable to a clinically ideal care plan accompanied by extreme distress and nonadherence.

Box 5. Ethically informed recommendations for managing nonadherent patients

- › Take a patient narrative approach, seeking to understand the patient's story and the reasons for their nonadherence.
 - › Actively display compassion and avoid appearing judgemental, remaining aware that patients may feel judged for their actions.
 - › Educate the patient as to the risks of nonadherence, including the implications of their nonadherence for others.
 - › Establish behavioural contracts collaboratively with the patient that set clear limits for what will be tolerated.
 - › Consider the use of technology (such as SMS notifications) to improve adherence.
 - › Adopt a multi-disciplinary approach where appropriate, involving, for example, psychologists and social workers.
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- Develop clear policies on responding to nonadherence (including when involuntary discontinuation might occur) and educate patients about them.

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